

Global Alliance Family History Tool Inventory and Statement of Best Practice

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Sage Bionetworks

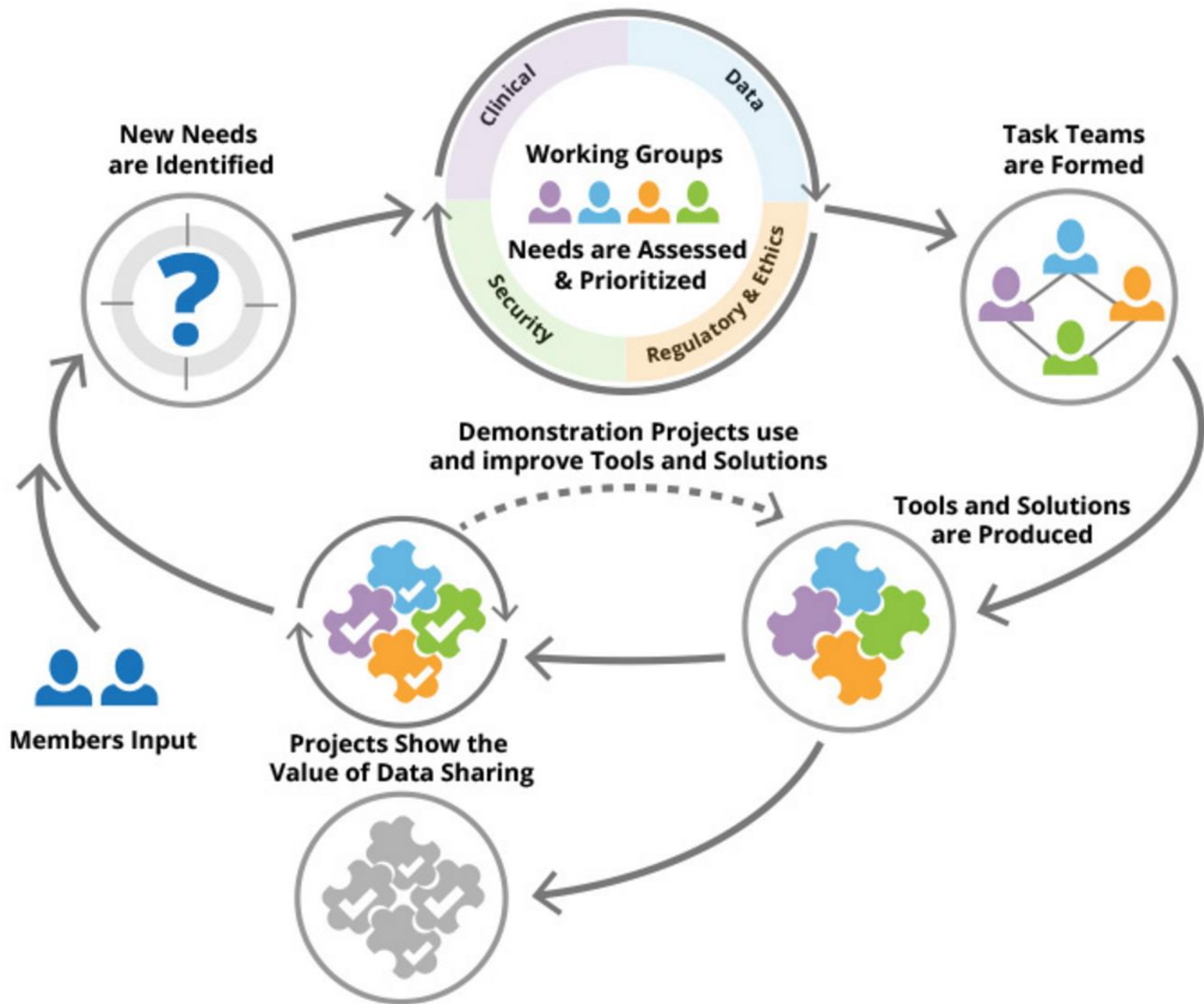
Disclosures

- Until June 2015, I lead clinical development and implementation of MyFamily, Cleveland Clinic's family history and risk assessment tool
 - No current compensation. Unexercised 10% ownership in an invention disclosure through CC Innovations
- I am a current Board member of CancerGene Connect, a family history collection and risk assessment tool developed at UTSW that is now being commercialized
 - No direct compensation. Unexercised stock options of <1% of company value
- Untold hours of volunteer effort for the Global Alliance



Global Alliance
for Genomics & Health

- Non-profit, volunteer-powered global consortium catalyzing projects that help unlock the potential of genomic data
- Convenes global stakeholders to share and establish best practices and to cross-pollinate ideas and learning, fostering a culture of innovation and discovery
- ~400 member organizations – both public and private – including Sage Bionetworks (the non-profit where I work now)
- Funding from many sources including NIH/NHGRI



Global Alliance eHealth Fhx Task Team

- Convened in Q3 2014
- Built off of work done for NCCRT Fhx Task Group
- Mandate:
 - Create a standardized inventory of family health history collection and risk assessment tools being used in clinical care around the world
 - From this knowledge base, develop a statement of best practice highlighting current approaches to and challenges in enabling family history to guide clinical care

Original Fhx Task Team Members

- John Mattison (Kaiser, USA), eHealth lead for the Clinical Working Group
- Ed Conley (Farr Institute, UK)
- Jeff Greenberg (Kaiser, USA)
- Ingrid Winship (University of Melbourne, Australia)
- Grant Wood (Intermountain Healthcare, USA)
- Meg Doerr (Cleveland Clinic → Sage, USA)



Work products



Inventory

- A registry of all known clinical family history tools listing name, provenance, contact and clinical features
- Updated regularly (v4.1 live 6/10/16)
- Feature to allow public to suggest additions/edits soon live

Tool Name	Provenance	URL	Creators	Contact
<i>AncestryHealth</i>	Commercially de	https://ancestryhealth.com	AncestryHealth	memberserv
<i>CancerGene</i>	Academically de	http://cancer.gene.com	David Euhus, N	David Euhus,
<i>CancerGene Connect</i>	Academically de	http://cancer.gene.com	Previously UTS	richard@cag
<i>CancerIQ</i>	Commercially de	http://canceriq.com	Commercial co	info@canceri
<i>CRA Health (formerly Hughes RiskApps)</i>	Academically de	http://crahealth.com	Previously Har	Kevin Hughes
<i>Cyrillic</i>	Academically de	http://cyrillic.com	Managed by Al	enquiries@a
<i>Family Healthware</i>	Academically de	https://familyhealthware.com	Sanitas, Inc. ha	info@familyh
<i>Genial (Formerly Shire)</i>	Academically de	http://genial.com	Genial Genetic	Through web
<i>Health Heritage</i>	Academically de	http://healthheritage.com	Previously Univ	Bill Knaus, M
<i>Invitae Family History Tool</i>	Commercially de	https://invitae.com	Commercial co	Arianna Gian
<i>MeTree</i>	Academically de	http://metree.com	Genomedical C	Lori Orlando,
<i>My Family Health Portrait</i>	Academically de	https://myfamilyhealthportrait.com	US Surgeon Ge	fhh@hhs.gov
<i>MyFamily</i>	Academically de	http://myfamily.com	Cleveland Clini	cci@ccf.org
<i>Myriad FamilyHistoryTool</i>	Commercially de	https://myriad.com	Commercial co	contactus@n
<i>Our Family Health</i>	Academically de	https://ourfamilyhealth.com	Intermountain	Grant Wood
<i>Pediatric Family History Tool</i>	Academically de	http://pediatricfamilyhistorytool.com	GPCI, AAP, NCI	Bruce Lin, MF
<i>PC PAL - PedigreeXP</i>	Commercially de	http://pcpal.com	PC PAL (France	Laurent ROSS
<i>Pregnancy and Health Profile</i>	Academically de	http://pregnancyandhealthprofile.com	NCHPEG, Marc	Bruce Lin, MF
<i>Proband</i>	Academically de	http://proband.com	DBHi at The Ch	probandapp@
<i>Progeny</i>	Commercially de	http://progeny.com	Commercial co	Mike Bramm
<i>Trakgene (formerly Kintrack)</i>	Academically de	http://trakgene.com	Commercial co	info@trakger
<i>ZibdyHealth</i>	Commercially de	http://zibdy.com	Zibdy, Inc. (Cal	support@zibi

Statement of Best Practice

- Discusses strengths and challenges of current development landscape
- Provides rationale for recommendations
- Highlights issues to consider for developers and consumers
- v4 currently in development
 - Will include description of requirements fhx consent management system
 - Please share your comments!

Enabling Family History Use in Clinical Practice: a review of current practice and policy considerations

This is a living document created by the Family History and Pedigree Consent task group of the eHealth, Clinical Working Group of the Global Alliance for Genomics and Health. This document is open for comment and will undergo regular revision. If you have comments or questions about this document please contact Megan Doerr, MS, LGC (megan.doerr@sagebase.org).

Version: 3.2 (7Feb2016)

Purpose:

The purpose of this document is to highlight current approaches and challenges in enabling family history to guide clinical care for developers of clinically-oriented family history collection tools including both “stand alone” and EHR-integrated products. Additionally, this document provides an overview of key design features (and supporting rationale) of family history collection and analysis tools for potential consumer/purchasers.

Introduction:

The goal of family history collection within medical practice is to improve patient care. Family history plays a central role in assessing patterns of disease inheritance and estimating the risk of developing specific conditions. Accurate reporting of family history is essential to clinical care, facilitating appropriate management of patients and their families. Additionally, family history informs the

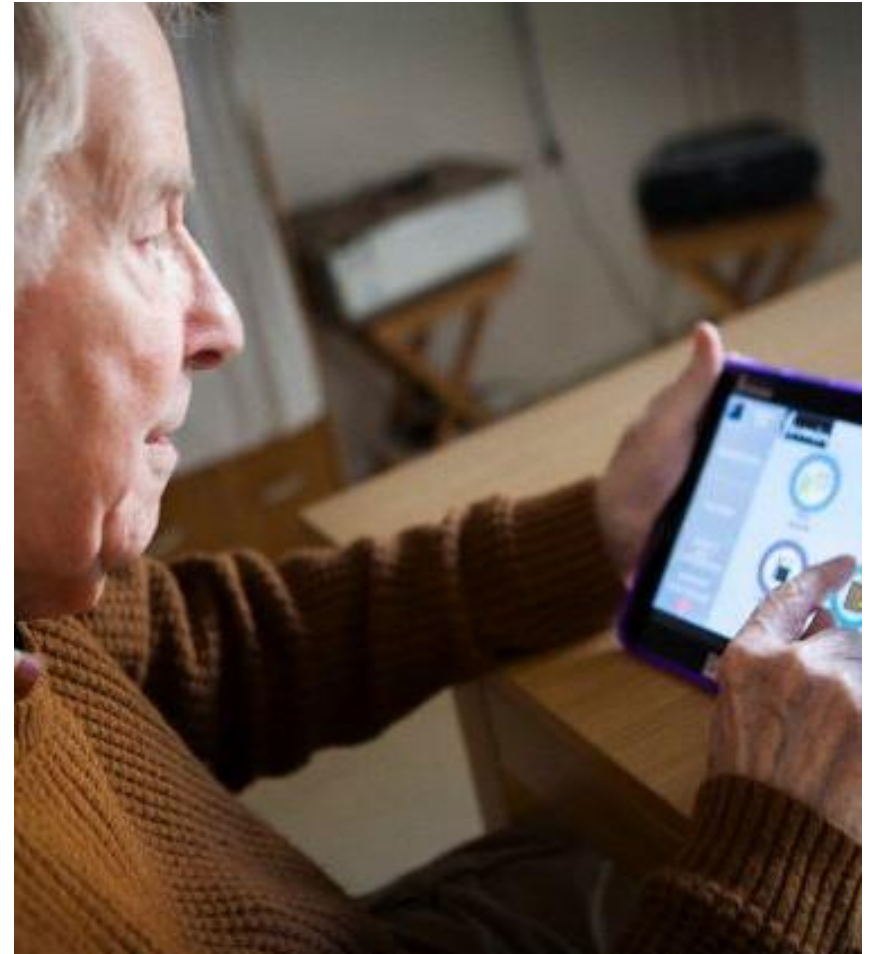
What we found



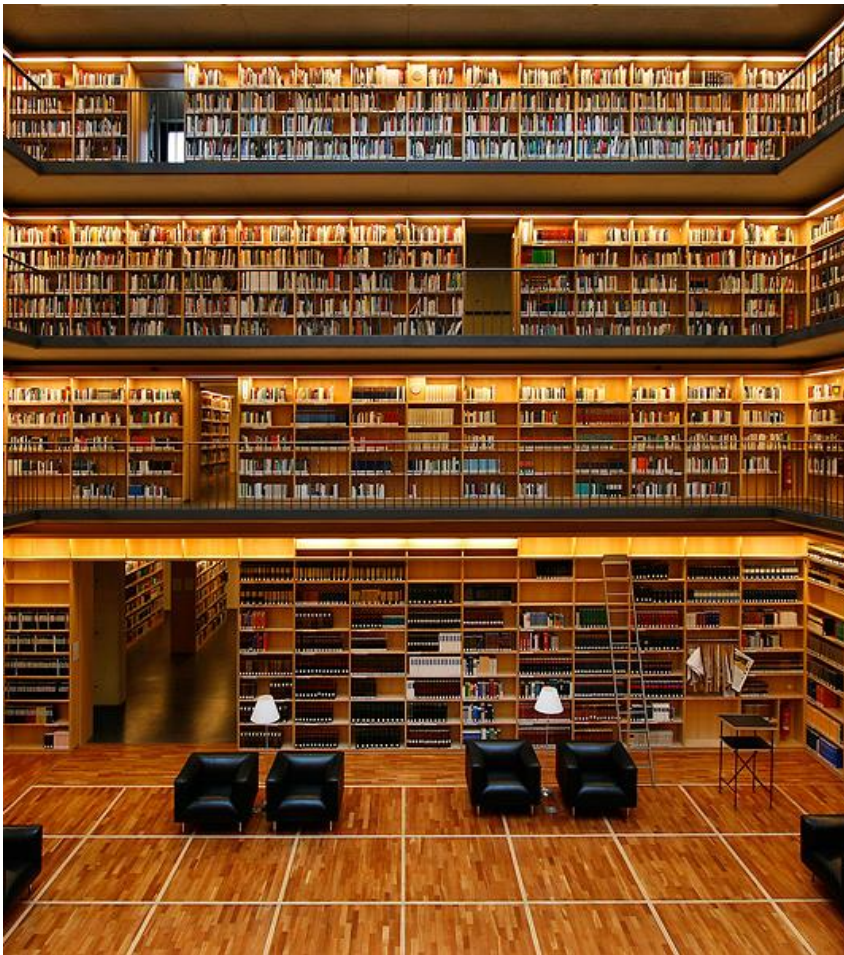
Design Features



Design Features



Design Features



lenses: very light.

Threads ; last PAP ~ 1.5

slim rod

PV: NO 14D string Se
14D hook used
\$140

7 - Ultrasound to check
position of 14D

RTC after USS

± DTC for removal

Design Features



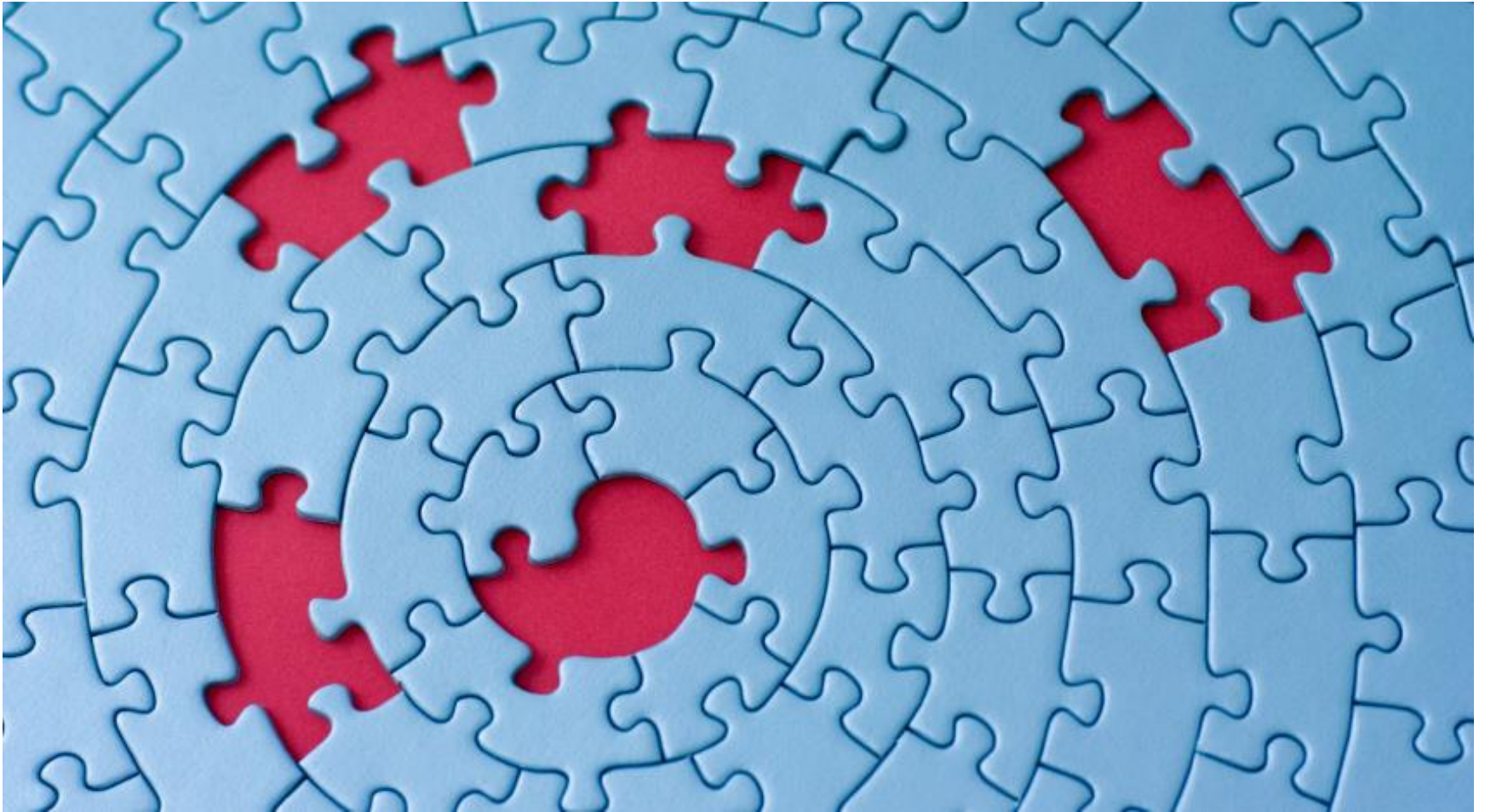
Design Features



Design Features



What's missing?



Needs



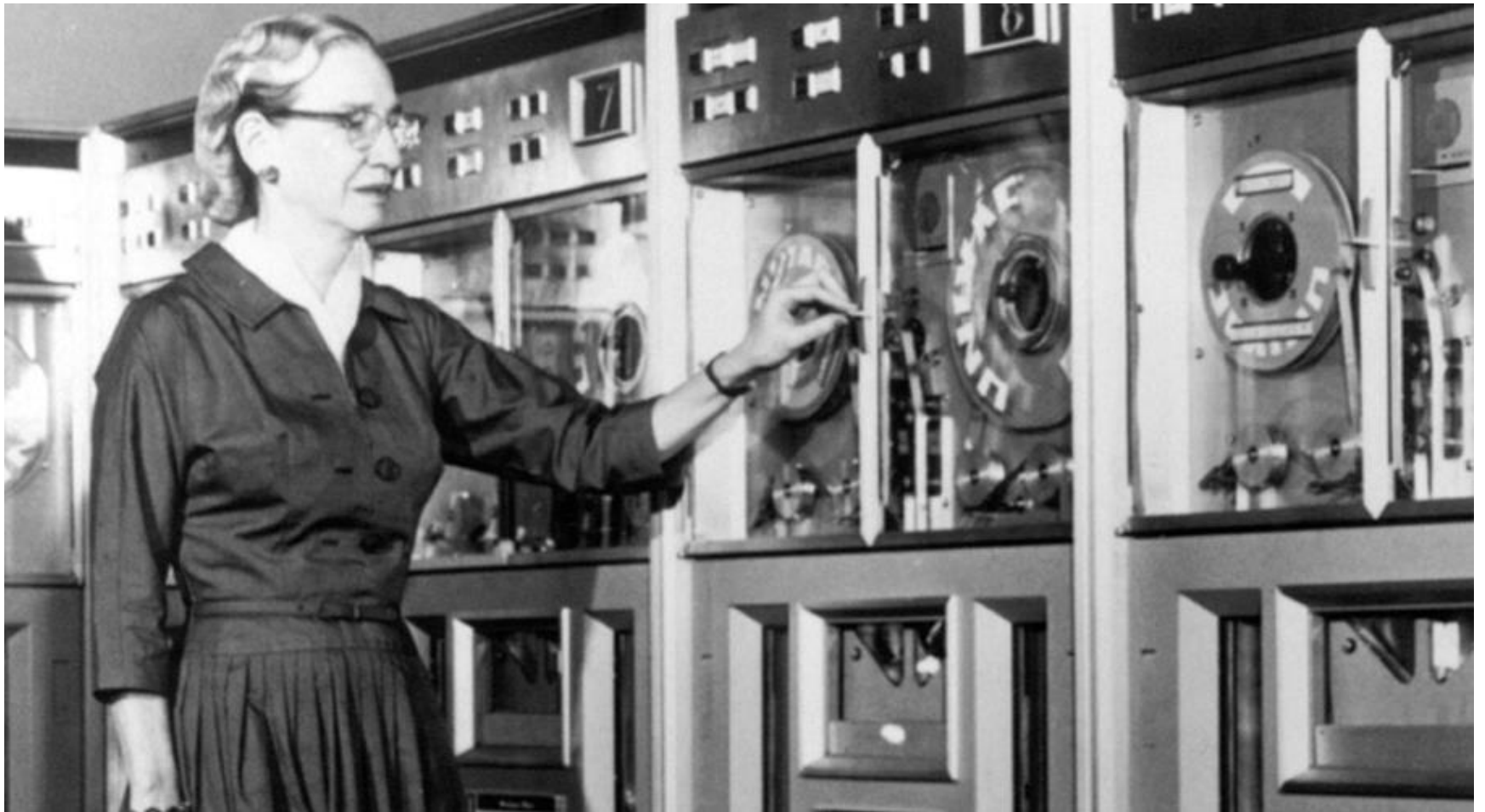
Needs



Needs



Needs



Needs



